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Note verbale dated 2 April 2001 from the Permanent Mission of Argentina to the United Nations addressed to the Secretary-General

The Permanent Mission of the Argentine Republic to the United Nations presents its compliments to the Office of the Secretary-General of the United Nations and has the honour to request, in accordance with the provisions of rule 9 of the rules of procedure of the Economic and Social Council, the inclusion in the provisional agenda for the Council's substantive session of 2001 of a supplementary sub-item under item 14, Social and human rights questions, entitled "Discrimination and genetic privacy", an issue to which the Government of the Argentine Republic attaches great importance, so that it may be dealt with in the framework of the United Nations.

In accordance with rule 12 of the Council's rules of procedure, an explanatory memorandum on the issue is annexed hereto for the Council's consideration.

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Annex

Explanatory memorandum

Although recent advances in genetic research have made it possible to identify the genetic origin of the diseases affecting human beings and to develop prevention and early detection strategies, this same genetic information can also be used to establish new parameters for classifying individuals on the basis of their "genetic quality", which undoubtedly will have unpredictable consequences for individual economic, social, cultural and professional development.

For example, individuals could be discriminated against with regard to access to education, jobs or health insurance if their genetic characteristics have the potential to manifest a disease in the future, even if those characteristics do not actually impede the efficient and productive performance of a given activity.

Paradoxically, while there are national laws and international conventions that protect individuals who currently manifest a genetic disease, there are no international instruments and few national laws against discrimination based on the techniques of "preventive genetics".

Such discrimination would affect not only those who have already been born, but also those yet to be born; this would amount to the establishment of a predetermined limit on an individual's capacity for personal development. Limitations on individuals' ability to obtain promotions at work, new opportunities or responsibility for special tasks would be based on their genetic background, not on their real capacity.

From a strictly economic standpoint, the economic incentive to discriminate on the basis of genetic information will increase in the near future because genetic testing to detect potential diseases is both increasing in effectiveness and decreasing in cost. This could lead to a rise in the use of such tests by enterprises.

Moreover, the fear of discrimination is growing, as shown by surveys which indicate that employers may soon begin to ask "genetic" questions when interviewing potential employees and that individuals would be unwilling to undergo genetic testing if employers had access to the results.

There is no scientific evidence of a link between an individual's genetic make-up and his or her ability to perform a given activity or job.

While the United Nations has developed standards relating to racism and to discrimination against women, disabled persons and older persons, no initiative on genetic discrimination has yet been presented in that forum. Therefore, the inclusion of a supplementary sub-item in the agenda of the Economic and Social Council would enable the United Nations to become decisively involved in this important issue, with the aim of:

(a) Involving and informing Governments and civil society to avoid situations in which individuals would be required to undergo genetic testing as a condition for the exercise of rights and benefits related to their personal, cultural, social and professional development;

(b) Alerting Governments and civil society to the use of genetic information to classify individuals in a manner that limits their opportunities for personal development;

(c) Providing adequate protection for privacy in the handling of genetic information for use in medical research and treatment.

Thus, the core aim of the proposal is to involve the United Nations and the international community in this problem, thereby preventing the emergence of new forms of discrimination by informing and preparing States to ensure due control over the use of genetic information.